

With Us and By Us: Patient-Centered Comparative Clinical Effectiveness Research Priorities for LGBTQ+ Older Adults

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Howard Brown
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INTRODUCTION

LGBTQ+ older adults represent a rapidly growing demographic yet remain largely invisible in patient-centered comparative clinical effectiveness research (CER). Despite a long-standing history of advocacy and resilience, this population faces significant health disparities shaped by systemic discrimination, social isolation, economic insecurity, and widespread medical mistrust. Their complex experiences at the intersection of aging, sexual orientation, gender identity, race and health status—including the experiences of people living with HIV—are often inadequately addressed in policy, practice and research.

To begin addressing this gap, Howard Brown Health, a federally qualified health center and one of the largest LGBTQ+ organizations in the Midwest, was funded by the Patient-Centered Outcomes Research Institute (PCORI) to explore patient-centered CER priorities specifically identified by LGBTQ+ older adults. This initiative brought together a patient-led Learning Collaborative (LC) made up of diverse LGBTQ+ older adults that was guided by human-centered design and implementation science frameworks. Through this LC, we created a space where older LGBTQ+ adults could speak about their own experiences, uplifting their voices and supporting their perspective—a radical initiative given the current governmental environment. As a group, the LC hopes to shape patient-centered CER with their needs, voice, and values at the center. This paper presents the process, findings and recommendations that were developed by the LC.

BACKGROUND

Barriers to Care

Healthcare access, supportive and stable housing, and community support systems look different for LGBTQ+ older adults compared to other older adults for a variety of reasons.¹ LGBTQ+ older adults are far more likely than heterosexual cisgender peers to have faced discrimination and social stigma. The effects of this prejudice and the current political climate directly influence resources on which LGBTQ+ older adults rely. Funding cuts to Medicaid and Medicare impact the 1.2 million low-income LGBTQ+ older adults that are enrolled in Medicaid.⁹ An increasing number of laws restricting LGBTQ+ affirming care, a medical education standard which still relies on a traditional and binary sex/gender system, LGBTQ+ specific clinical knowledge gaps, and a lack of appropriate cultural competency education, all make it difficult for LGBTQ+ older adults to access quality healthcare.^{4,5} A recent survey showed around 24% of LGBTQ+ older adults report having a negative health care experience within the past three years causing their health to worsen.³ This extends to care facilities—many LGBTQ+ older adults fear experiencing worsening health disparities, medical neglect, and mistreatment if they enter care facilities, such as older adult day care, residential aged care, palliative care, and end-of-life facilities. Many fear having to hide their LGBTQ+ identity (to go back into the closet) to receive equitable treatment and avoid discrimination in such settings. **These experiences compound with a general shortage of gerontologists prepared to care for older adults, making access to healthcare more difficult for LGBTQ+ older adults.**



BACKGROUND

Health Disparities

Experiences of discrimination and marginalization, both in healthcare and society, along with rising healthcare costs, increase health disparities that LGBTQ+ older adults experience. **LGBTQ+ older adults are twice as likely to be single and live alone, four times less likely to have children than their heterosexual cisgender peers and are more likely to face poverty and homelessness.** LGBTQ+ older adults have a heightened risk of chronic health conditions, disabilities, and poor overall health. They experience substantial challenges in managing chronic pain, show higher rates of cardiovascular disease, arthritis, kidney and lung disease,^{6,7} and struggle with higher rates of substance and alcohol issues.⁸ This heightened risk also extends to mental health. **LGBTQ+ older adults have a higher likelihood of experiencing mental health disparities including depression, anxiety disorders, multiple health risk behaviors** (e.g., suicide ideation, plans, and attempts), and higher levels of social isolation and loneliness compared to their non-LGBTQ+ peers.¹⁰



BACKGROUND

LGBTQ+ Older Adults and HIV

Older adults living with HIV (LWH) experience disparities that are not being properly addressed which increase as this population continues to age. **This includes an increased prevalence of chronic illnesses like cardiovascular disease, malignancies, osteoporosis, cognitive impairment, frailty, and disability, which may result in a higher risk of hospitalization linked to the concurrent use of multiple medications.**^{11,12} Along with these physical health disparities, older adults LWH experience unique social and economic disparities. A study of older adults LWH found 71% reported experiencing both ageism and HIV stigma, and 56% reported experiencing rejection from service providers, family, friends, and church members. This may leave many older adults LWH disconnected from traditional social support networks, increasing loneliness which, along with HIV stigma, has been related to increased depression.¹³

HIV stigma, discrimination-based job loss, fatigue, and periodic hospitalization caused by HIV-related illnesses may also make it challenging for older adults LWH to establish strong economic safety nets. Further barriers include the high costs of healthcare and lack of insurance coverage for older adults LWH which contribute to economic instability.¹⁴ **Without intentional interventions focused on meeting the specific needs of LGBTQ+ older adults and older adults LWH, stark disparities in physical and mental health outcomes will continue.**²

PROJECT FRAMEWORKS AND GUIDING PRINCIPLES

Using a steering committee model, the project launched with the creation of an LGBTQ+ older adult patient-centered Learning Collaborative (LC). The LC is led by LGBTQ+ older adult patient members of differing ages, sexual orientations, races, genders, ethnicities, abilities, and backgrounds. The LC created a set of frameworks and guiding principles that provided scaffolding for all initiatives.

Frameworks included an essential focus on inclusivity and intersectionality, social justice, and human-centered design. Social justice principles of health and racial equity were integrated to ensure that the project did not perpetuate the systems of oppression that impact the health and wellness of LGBTQ+ older adults. Human-centered design research principles, focusing on the participant, their needs and desires, were incorporated into all aspects of the LC and its initiatives. The LC was educated in implementation science concepts as well, such as implementation barriers and rapid qualitative analysis.

**Inclusivity and
intersectionality**

.....

Social justice

.....

Human-centered design

Using its frameworks as a platform, the LC created the following 11 Guiding Principles:

1 **LGBTQ+ Older Adult Patient-Centered**

Everything we do will be patient-centered on LGBTQ+ older adults. LGBTQ+ older adult patients will guide our LC and will be centered as we plan all project activities. We will ensure that our meetings and workshops are accessible and comfortable for our LGBTQ+ older adult participants.

2 **All Voices are Valuable**

All voices in our LC are valuable and we can learn from everyone. There are no hierarchies in identity, and all people can make an important contribution.

3 **Respectful Communication**

We will speak with each other respectfully, using preferred names and pronouns for all members. If we make a mistake, we will apologize, correct it and avoid making that mistake again. We communicate with others about the project in respectful, honest ways. In our discussions, we are invited to share what we are comfortable sharing. We agree to respect the personal experiences of others and will not share personal information outside of our meetings.

4 **Co-learning**

We all have things to learn and things we can share and teach. We will work together to learn and agree that this learning will make us more successful in our goals. All LC members, including LGBTQ+ older adult patients, providers, researchers, advocates and project team members will stay open to learning from each other.

Using its frameworks as a platform, the LC created the following 11 Guiding Principles:

5 Health Equity

Our goal is to create tools that help offer the very best health and healthcare to all LGBTQ+ older adults in a way that meets their specific needs. We do not endorse a ‘one-size-fits-all’ approach and instead believe that patient-centered CER and healthcare should be specifically adapted to meet LGBTQ+ older adult needs in a way that helps them lead full, healthy lives of their choice.

6 Health Justice

In addition to health equity, our goal is to strive for health justice. Health justice reaches a step further than health equity and works to remove barriers to healthcare and active involvement in patient-centered CER. It focuses on the elimination of health disparities and aspires to help everyone access high quality health care and healthy living conditions that meet the needs of LGBTQ+ older adults.

7 Practical Strategies for Health Outcome Improvement

We will focus on practical, realistic solutions that can be used by us/others to improve LGBTQ+ health outcomes and will create useful tools to increase patient-centered CER capacity. We will do our work with an intentional focus on true use to the community.

8 Community Engagement and Empowerment

We believe LGBTQ+ older adult community engagement and empowerment are critical components to all our work. Participation in our LC and workshops will help empower LGBTQ+ older adult to participate in patient-centered CER to develop better healthcare for themselves and their community. Self-acceptance and being a part of all work for/about our community is empowering and impactful. We encourage ourselves and each other to engage and participate fully.

Using its frameworks as a platform, the LC created the following 11 Guiding Principles:

9 Try It, Improve It, Try It Again

We don't expect to get everything just right the first time we design or discuss something. We will actively learn from each thing we do and channel that learning into improving the tools we develop and the workshops we create. We will try something, assess it, learn from it and improve it and then test it again.

10 Find Joy in Taking Action

We embrace our identities and our LGBTQ+ older adult communities. We build on our strengths and resilience, finding joy and positivity in the work we are doing together.

11 LGBTQ+ Liberation

We believe that healthcare and healthcare systems should be LGBTQ+ affirmative and should offer LGBTQ+ people care that fits their unique needs. Healthcare is inadequate and ineffective if it requires LGBTQ+ people fit into services that were built to serve only straight and cisgender people. Liberation fuels power-building and self-advocacy which improves health and wellbeing and uses power to evolve systems of care.

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This initiative was designed to ensure that patient-centered CER priorities of LGBTQ+ older adults were identified with them and by them. Our process was grounded in equity and authentic engagement, with a goal to raise the voices of marginalized people, and a belief that community members are experts in their own lives. The following steps outline how we worked together to co-create the findings presented in this white paper.

Forming a Project Team

A project team was identified to facilitate the project and assemble a learning collaborative (LC) of LGBTQ+ older adults. The project team included five team members with expertise in LGBTQ+ older adult health, with two identifying as older adults themselves.

Gathering Stakeholders and Forming a Learning Collaborative

We established a Learning Collaborative composed of LGBTQ+ adults over the age of 50, a microcosm of the older adult population. Members were recruited through local providers, community organizations, and word-of-mouth referrals. The inclusion criteria included self-identifying as LGBTQ+ and being 50 or older. The LC was intentionally designed to reflect a range of gender identities and sexual orientations among LGBTQ+ adults. Members included cisgender women and men, and transgender and nonbinary people. Sexual orientations represented included gay, lesbian, bisexual, and queer identities. This diversity ensured that discussions of health research priorities captured the complex intersections of gender identity and sexuality in later life. While the LC was demographically diverse in terms of gender identity and sexual orientation, we acknowledge that racial and ethnic diversity was limited. Most participants identified as White, with fewer members identifying as Black, Latinx, or multiracial. It must be stated that

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the goal of diversity was only partially achieved. The LC members identified are representative of those who were easily engaged, not those who were out of reach. Greater diversity, including differently abled people, would add richness of experience and perspectives otherwise unrepresented. LC members indicated that the final group members represent and reflect the larger issues of representation in healthcare today.

DEMOGRAPHIC CHARACTERISTICS OF LEARNING COLLABORATIVE PATIENT MEMBERS (N=9)

CHARACTERISTICS	FREQUENCY	PERCENTAGE
AGE		
50 – 60	2	22%
60 – 70	2	22%
70 – 80	4	44%
80 – 90	1	11%
RACE/ETHNICITY		
Black/African-American	2	22%
Hispanic/Latino	1	11%
White	6	67%
GENDER IDENTITY		
Transgender Female	3	33%
Cisgender Female	2	22%
Cisgender Male	4	44%
SEXUAL ORIENTATION		
Lesbian	4	44%
Gay	3	33%
Bisexual	1	11%
Queer*	1	11%

* See page 28

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Engaging Stakeholders and Creating a Shared Space for Dialogue and Decision-Making

In addition to LC patient members, a stakeholder group of local academic and community experts recognized as supporters of LGBTQ+ older adults, with experience in aging, LGBTQ+ health, patient-centered outcomes research, and community advocacy were recruited. Together, LC members and stakeholders met in different sessions to share knowledge, identify gaps, and co-create solutions. Many stakeholders had previously conducted patient-centered CER or worked directly with the community, giving the LC insight into systemic barriers and research gaps.

Collecting Community Insights

LC members and the project team worked together to develop an interview guide for focus groups. We held virtual and in-person focus groups across the city to ensure that we were capturing experiences across neighborhoods, providing an affirming and accessible environment to encourage openness and trust. We heard directly from community members who identified as LGBTQ+ older adults, our stakeholders, and LC members. During community and stakeholder focus groups, LC members attended as co-facilitators and field-note takers with the goal to reflect multiple perspectives in our findings.

Co-Learning and Rapid Qualitative Analysis (RQA)

LC members and project staff received training in Rapid Qualitative Analysis and worked side-by-side to review transcripts and field notes. Together, we looked for common patterns, powerful quotes, and shared priorities across all the conversations and notes. This was a process of reflection and co-interpretation, and most importantly, a process which honored community wisdom.

FINDINGS/RESULTS

Upon completion of several cycles of rapid qualitative analysis, the project team and LC members identified six broad domains that described collected themes, subthemes, and influencers in LGBTQ+ older adult health and patient-centered CER. The domains are not ordered in any priority – all were deemed equally important. Overall, the domains identified a narrative for older LGBTQ+ adults' experiences with healthcare and their patient-centered CER priorities. Four of the domains reflect experiences related to wellbeing, self-advocacy, access to care, and personal connectedness, while the remaining 2 domains focus specifically on patient-centered CER priorities and engagement. While seemingly distinct, each of the 6 domains are interrelated, influencing each other and patients lived experiences. Each domain is described below with representative quotes by LGBTQ+ older adults gathered from focus group participants.

DOMAIN 1: ASPECTS OF HEALTH AND WELLBEING

The first domain is **Aspects of Health and Wellbeing** which includes four themes: **Community Connection and Socialization, Physical Health, Mental Health and Emotional Wellness, and Financial Health**. This domain highlights the elements of health that are important to LGBTQ+ older adults and that lay foundation for positive health outcomes and thriving.

Community Connection and Socialization

This theme described the importance of affirmative community connection as a contributor to health. Whether through connection with specific subgroups (gay men living with HIV) or broad community contact, LGBTQ+ older adults identified this as a critical component of health that directly

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impacts their ability to heal and recover. Connection counteracts isolation which fuels depression. Social connection can occur in a range of settings, such as activities, social networks, support groups and volunteering. It was noted that a lack of connection with or estrangement from family directly contributed to loneliness and isolation.

“*I concentrate a lot on trying to build friendships, communicate with people every day.... So that's the main thing is to reach out to communicate wherever you have friends and share each others' problems and try to solve these problems.*”

Physical Health Through Activity

This theme identified the importance of remaining active and exercising (e.g., going to the gym, dancing, walking) as critical aspects of health and wellbeing. LGBTQ+ older adults described a challenging cycle of physical limitations that interrupted independent access to exercise which, in turn, further limited physical capacity. This created worries about self-care when older adults experience reduced physical capacity through worsening health or surgery. Access to practical help, with companionship and encouragement for activity and exercise, were important supports. Healthy nutrition and adequate hydration (crucial to provide thermoregulatory support, infection prevention, mobility, and to aid cognition, mood, and sleep) help sustain health.

“*For me it's all about self-care and I've got to take care of myself...And then there's getting my steps in, in any right, it's getting my rest, also partnering with primary care physician, and just being true to who I am regardless of somebody else's agenda.*”

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Mental Health and Emotional Wellness

This theme included sustained cognitive capacity and ability to make decisions, connection to others for emotional wellness, and access to mental health resources like counseling and therapy. LGBTQ+ older adults noted the importance of sustained cognitive capacity to ensure continued independence and community participation. In addition, it was noted that living authentically and unapologetically, with a focus on pride and gratitude supported LGBTQ+ older adults' mental well-being. The impact of caregiving for other LGBTQ+ older adults can influence a caregiver's mental health.

“...mental health, I think, is really important... so that [LGBTQ older adults] are not lonely.”

Financial Health

This theme addresses the importance of financial health and how financial well-being increases access to critical resources (i.e., health insurance, healthcare, alternative healthcare, supportive care, food, housing). Limited or scarce financial resources creates a cycle of worsened health which, in turn, further drains resources. LGBTQ+ older adults noted that retirement resulted in reduced resources when health care costs are increasing. Class and socio-economic status influence the ability to afford exercise and practical assistance, to access quality food, and afford rent in a neighborhood that is safe.

“It affects your social experience... they're interdependent, but the financial is really a key piece for me. And I think, in theory too, it undergirds and affects all areas.”

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DOMAIN 2: SELF-ADVOCACY AND HEALTH INFORMATION RESEARCH

The second domain, Self-Advocacy and Health Information Research, revealed the need for reliable sources of health information with two themes focusing on the need for essential knowledge to inform health decisions and reliance upon self-advocacy. The concepts developed here grew out of multiple experiences with traditional medical institutions that bred mistrust and mainstream sources that delivered unreliable information.

Critical Need to Gather Essential Knowledge to Inform Health Decisions

This theme is centered on the need for trusted health information sources, whether that information comes from community (other seniors), friends and family, LGBTQ+ organizations, providers, and the internet. However, available sources may be both trusted and misleading, or in some cases, incorrect and unreliable. Providers are respected but can lack nuanced knowledge about LGBTQ+ geriatric patients specifically. Technology, while useful and convenient, can be difficult for some seniors to access and navigate.

“So basically ... I am in this situation. I don't find any information to help me. I don't find online. Can you help me? Can you give me some resource? I think it's because we actually have the tendency to see online first, but I would say online second [and talk to people first].”

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Reliance on Self-Advocacy

Searching for trustworthy resources falls to each older adult to do on their own. Looking for healthcare information sources that facilitate access is limited by personal vulnerability, knowledge, and community oppression. Mistrust of providers, lack of providers' education in LGBTQ+ best practices, and lack of experience with geriatric patients influences older adults' ability to attain the care they need. This generation of older adults has not been taught how to advocate for themselves and navigate complex systems and was actively discouraged from doing so in their past.

“...I’m finding of late the main thing that affects my health is my own ability and willingness to do research. Don’t just accept the doctor’s diagnosis, prognosis or whatever, find out for myself because I personally am managing much better through my research....”

DOMAIN 3: ACCESSING CARE

The third domain, Accessing Care, includes three themes that focus on safety and characteristics that LGBTQ+ older adults would like to see in their providers and healthcare systems—much of this predicated on lives spent functioning within a system that does not readily acknowledge their unique needs as they age. Access to healthcare among different LGBTQ+ subpopulations is imbalanced, with some groups receiving the bulk of recognition and resources. This can reduce access to care, leading to worsened health and increased feelings of invisibility. This must be explored to improve representation.

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Self-Protection/Safety

Aging is a challenge for everyone, not just LGBTQ+ older adults. This safety theme reflects a profound concern (fear) of LGBTQ+ older adults to share their LGBTQ+ identities with their providers. This simple disclosure is challenging as it can lead to undesirable outcomes, negative reactions and potential consequences in multiple healthcare systems. LC members emphasized that the feeling of fear is bolstered by the very real and concrete risk of mistreatment or harm when their identity is known.

“*So it’s really very difficult to be able to be yourself, which then weighs tremendously not only on your mental and emotional and spiritual health, but it breaks your body down that you have that stress and cortisol of having to keep your secrets.”*

Characteristics We Need in Providers

Specific qualifications in providers would improve the experience of LGBTQ+ older adult patients in healthcare spaces, such as providers who are a part of the LGBTQ+ community themselves. Overall, however, culturally competent LGBTQ+ inclusive providers with knowledge about ageism and awareness of the intersection of their various identities are likely to improve the experiences of LGBTQ+ older adults in healthcare.

“*Medical schools do not teach those things ...cultural competency ... we’re dealing with doctors who are not necessarily attuned to the experience that we’ve had ...the care that we should be receiving from them ... there’s the [lack of] intersectionality of cultural competence in caring for Black patients, Latino patients--”*

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Characteristics We Need in Healthcare Systems

Likewise, healthcare systems must develop welcoming spaces in which all staff are properly trained in diversity and culturally safe and gender affirming best practices in LGBTQ+ older adult care. This can be achieved by creating user-friendly paperwork and having benefit navigators who are well-trained in financial assistance and insurance used by older adults (e.g., Medicaid). LC members also highlighted the need for relationship-building between healthcare centers and senior housing to make processes, such as getting tested, accessible for older adults by having them offered at their residence.

“*[Even] With a college education and nursing background, I sometimes still struggle to negotiate the health care system. I’m a resource to my friends and family because it’s so complicated to get figured out...*”

DOMAIN 4: INTERPERSONAL CONNECTION

The fourth domain, Interpersonal Connection addresses multiple areas of concern related to isolation and the need for LGBTQ+ older adults to develop vital support networks that include biological children, chosen family of all ages, and community peers. Additionally, mentorship and bi-directional intergenerational relationships were identified as potential supports.

Chosen Family as Critical Support Networks

Repeatedly, chosen family was highlighted as a primary resource for support and care, and as a trusted resource. However, loss of peers currently dying from old age and previously from AIDS has left a legacy of PTSD and lingering concern about availability of chosen family.

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“The other thing that stands out for me is chosen family, [it] has been of utmost importance for me. Being available to them as well. So it isn’t about just what I get but what I give. That has been very much a part of ... “healing.””

Caregiving is a Safety Net and a Burden

Frequent absent or estranged family (e.g., biological children or siblings) has LGBTQ+ older adults turning to their peers for support, especially in emergent care situations when they fear harm from staff in long-term care facilities when their LGBTQ+ identities are known. This fear is compounded by seeing peers struggle, not having day-to-day practical assistance, and having a perceived lack of care in the future.

“We should have a network of LGBTQ caregivers, homemakers. That is a good idea because some people aren’t comfortable [with LGBTQ+ older adults] ...So we need a network built up where we can get the proper care ...And that network should be able to reach out to those people that are working at other places that are gay-friendly.”

Mentorship

Intergenerational relationships serve multiple purposes, including sharing the importance of experience, legacy, and being a role model for younger generations. At the same time, younger LGBTQ+ people have much to share with older adults. This intergenerational connection can foster a sense of belonging in the greater LGBTQ+ community and can provide assistance to older adults. Older LGBTQ+ adults strongly believe that their lives and struggles established the foundation upon which young LGBTQ+ people

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stand and older adults want to nurture this relationship. However, multiple barriers exist to establishing these intergenerational relationships. Barriers can include concerns about ageism, a perception of younger people that older LGBTQ+ adults may be predatory, a perception of older adults that they may be taken advantage of, and lack of willingness of younger people to listen to discussions about health concerns that don't impact them yet.

“ *Well, the whole thing is both sides need to mentor each other. We can teach as being older. They can teach as being younger, and that brings it all together that we can begin to understand each other.*”

The last two domains center on LGBTQ+ health research, patient-centered CER priorities and how to authentically engage LGBTQ+ older adults in patient-centered CER.

DOMAIN 5: RESEARCH PRIORITIES

The fifth domain is **Research Priorities** and includes three themes: **Research Familiarity/Knowledge, Research Approaches and Patient-Centered CER Topics**. This domain describes LGBTQ+ older adults' existing knowledge about patient-centered research, high value approaches to integrate into patient-centered CER, and specific research topics to explore in patient-centered CER with LGBTQ+ older adults.

Research Familiarity/Knowledge

When asked, few LGBTQ+ older adults were familiar with existing research or research that is in process with their community. LGBTQ+ older adults were aware that the existing research structures are changing, noting fewer

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available funding sources for LGBTQ+ older adult focused health research. The LGBTQ+ older adult community felt it was important to seek out relevant research publications and opportunities, if available, and, when unavailable, to examine hospital and health center values to determine trustworthiness and potential quality of care.

“*I was so excited to see this [project]. .. I jumped all over it and I was really grateful to see it because I come from research, the history of my mom, background, everything, and I participate in research when I can because I think it’s really important.*”

Research Approaches

This theme includes the critical importance of utilizing community-based, intersectional approaches in patient-centered CER and in participant engagement. LGBTQ+ older adults advocated for the intentional inclusion of LGBTQ+ people in general and LGBTQ+ older adults specifically in patient-centered CER. LGBTQ+ older adults advocated their inclusion in not only CER specifically focused on LGBTQ+ older adults but also in CER exploring specific, chronic conditions. This theme also highlighted an encouragement to include unique/distinct identities based on race/ethnicity, age, gender identity, sexual orientation and geographic area (urban v. rural) when recruiting for patient-centered CER.

Patient-Centered CER Research Priority Topics

This theme included all patient-centered CER topics identified by LGBTQ+ older adults. The topics are included below by cluster: medical, mental health, age-specific, HIV, increasing gerontological expertise, and improving patient self-advocacy.

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- **Medical Health Cluster:** Suggestions included patient-centered CER initiatives to explore the most clinically effective treatments for LGBTQ+ older adults with cancer, heart disease in women, diabetes, osteoarthritis, autoimmune diseases, long-term effects of gender affirming hormone dosing, alcohol abuse, smoking cessation/nicotine use, and reducing the impact of secondhand smoke.
- **Mental Health Cluster:** Suggestions included patient-centered CER initiatives to explore the most clinically effective treatments for LGBTQ+ older adults to reduce loneliness, social isolation, depression and suicidal ideation, improving health outcomes as a result. In addition, patient-centered CER could explore the efficacy of different interventions to assist LGBTQ+ older adults to prepare for aging (specifically lesbians and transgender people) and to prepare for death and dying.
- **Age-Specific Cluster:** Suggestions included patient-centered CER that explores post-menopausal physical and mental symptom relief, post-prostate cancer sexual health, post-hysterectomy recovery, post-oophorectomy recovery, reduction and management of dementia, dehydration, sexual health and post-retirement resurgence of sex (e.g., hook ups, porn, sex work).
- **HIV Cluster:** This included patient-centered CER to increase engagement and retention of LGBTQ+ older adults living with HIV in HIV care and PrEP/PEP use.
- **Increasing Gerontological Expertise Cluster:** This included patient-centered CER to develop and sustain providers' and health care systems' effectiveness in engaging and retaining LGBTQ+ older adults in affirmative health care.
- **Improving Patient Self-Advocacy Cluster:** This cluster includes patient-centered CER to increase effective older adult patient self-advocacy in medical care and increase informed medical decision making of

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LGBTQ+ older adults. LGBTQ+ older adults will experience improved health outcomes when they are able to confidently self-advocate. This is especially important since generationally older adults haven't been taught or encouraged to do so. Patient-centered CER could explore the most effective interventions to encourage older adults to ask about treatment alternatives, directly voice their concerns, ask medical providers questions, and communicate their preferences and end of life choices.

DOMAIN 6: AUTHENTIC ENGAGEMENT IN RESEARCH

The final domain, Authentic Engagement in Research, describes a mixture of underlying mistrust of healthcare research and a strong desire to contribute to research with purpose.

General Mistrust

This theme highlights fears that LGBTQ+ older adults have about participating in patient-centered CER. LGBTQ+ older adults discussed worries about confidentiality and concerns about sharing personal information (social security number, demographic information, identity descriptors). This concern heightened for especially vulnerable populations including people who are disabled, queer immigrants, and transgender people. LGBTQ+ older adults noted increasing danger in legislation and government action, with efforts made to purge existing research results. The identity and community trust of an organization conducting and funding LGBTQ+ older adult patient-centered CER is of critical importance. Without that existing trust, LGBTQ+ older adults will not engage in research.

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“Something I’d like to add that I didn’t hear during our focus group is trust. If you offer a service and you expect having people coming to use your services one thing that’s really important because my experience when I come to a place and I feel I am not respected, I’m not heard, I’m not listened to, I distrust the system, I distrust the service which the organization offers. And so if I try a new place...the first thing I want to feel [is] that I can trust this person in front of me when I speak to them.”

Recruitment and Dissemination

This theme includes encouragement to establish social network recruitment strategies for authentic and diverse population engagement. Using trusted sources to communicate with potential participants increases the possibility of engagement and retention in patient-centered CER. Trusted sources can include friends, social network contacts, organizations, and providers. Helping potential participants see the positive health impact and personal benefit of patient-centered CER will increase engagement now and in the future. Lastly, LGBTQ+ older adults identified a need for consistency in community recruitment and dissemination of findings.

“This is the first time in my new era of being older adult of being included in a focus group. If research has been conducted and reports have been written and printed, I have not read them. So I’d be curious to know first what is happening, who’s conducting it, who’s interested, and to whom it is available also. And how is it being used to inform best practice. And what metric is used to determine if it works or not...”

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Personalized Purpose

This theme identified the value and positive impact of activating queer “civic” pride, a sense of personal value and contribution, as a motivator to participate in patient-centered CER. Communicating the impact on community health and having patient-centered CER that includes LGBTQ+ older adults can compel participation and create pride in increasing community representation. This theme also includes some concrete suggestions for successful engagement: use trusted spaces and trusted sponsors, keep groups small, design the research to help participants reduce social anxiety, compensate participants in ways that signal real value of their contribution, and keep durations “short and sweet” to make it easier to participate.

“...people that I come in contact [with] are so excited to be able to participate in a research study about us that is if the opportunity is there that they would just do it. ...having a centralized place where people can find these research opportunities and making sure that we are all advocates to find the mixed groups...”

LEARNING COLLABORATIVE SUMMARY GUIDANCE

Our project goal was to identify LGBTQ+ older adult community-driven, patient centered CER priorities and to explore LGBTQ+ older adults' perception of their health, care needs and resilience. The project has met its goals and has offered rich guidance to future patient centered CER research teams, including researchers, patients, providers, caregivers, and advocates. Reflecting on the narrative above, the LC identified some consolidated guidance for future patient centered CER.

1. It is critically important to include research participant populations that are frequently overlooked and may not be comfortable stepping forward to participate in patient centered CER.
2. Researchers should carefully examine and interrupt their biases and assumptions through self-exploration prior to leading patient centered CER with LGBTQ+ older adults or other marginalized groups.
3. Researchers should strive to understand and recognize the cultures and worldviews of research participants and intentionally interrupt cisgender, heterosexual, racist and sexist biases.
4. Enrich communities that contribute to research and developing creative community-based dissemination plans for every study, project and initiative.
5. Shared results and findings must be accessible and understandable to patients, caregivers, providers and researchers and made actionable to improve care quality.

6. Make results geographically actionable so they can be applied and tested in a variety of communities, including both rural and urban settings.
7. Proactively identify limitations of research, identifying the voices that were not found or included.
8. Embrace the joy of doing this work – personal satisfaction with making contributions and presence is critical (even for people who are quiet!).

This project revealed factors to inform future patient centered CER with LGBTQ+ older adults. At the same time, it illuminated aspects of healthcare that require reform to be inclusive and welcoming of LGBTQ+ older adults. LC members voiced strong concern about the lack of inclusive and affirming health systems (insurance navigation, access to affirmative medical/behavioral/social care, culturally competent multidisciplinary health care staff) that directly affect the patient-provider relationship and, ultimately, patients' health, well-being, and quality of life as they age. Increased demand for qualified practitioners and evidence-based interventions to support the increasing number of aging LGBTQ+ patients was a major topic revealing a persistent need for tailored patient centered CER.



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NOTE FOR PAGE 9

The term queer in this context refers to sexual orientation, representing an openness to a sexual partner that falls outside of the heterosexual mainstream.¹⁵ More examples of the definition of queer can be related to politics, demanding questioning and upending of mainstream conventions, gender identity that falls outside the gender binary, or its' use as an umbrella term for the entire LGBTQ+ umbrella of identities. LC members wanted to state that while some older adults have adopted this term, many do not advocate this use of the term as they understand it to be derogatory.

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